

From DEPARTMENT OF CLINICAL SCIENCES,
DANDERYD HOSPITAL
DIVISION OF SURGERY
Karolinska Institutet

and

Sophiahemmet University College,
Stockholm, Sweden

LIFE SITUATION IN PEOPLE WITH PERIPHERAL ARTERIAL DISEASE AND THEIR FAMILY MEMBERS

Louise Egberg



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“Where the sun shines, there too is shadow.
Be illumined by the light of knowledge no less than by its shadow.”

Halcolm - qualitative inquiry muse (1980-) by Patton, 2002

ABSTRACT

Life with peripheral arterial disease and the resulting impaired walking ability leads to major limitations in daily life and a decreased quality of life. The overall aim of this thesis was to generate understanding about the life situation among people living with peripheral arterial disease and their family members.

The outcomes after percutaneous transluminal angioplasty interventions both proximal and distal to the inguinal ligament were assessed by collecting data by means of chart review using a study specific protocol. The results show a connection between proximal intervention and age as well as proximal intervention and smoking. Patients in the proximal group were younger and more frequent smokers or former smokers and hematomas/bruises as a complication were more common among non-diabetic patients (**Paper I**).

Health related quality of life in patients with peripheral arterial disease undergoing percutaneous transluminal angioplasty intervention was investigated using a general questionnaire (EQ5D) as well as a disease-specific questionnaire (CLAU-S) translated into Swedish for this study. The health related quality of life was improved both one month and one year after the percutaneous transluminal angioplasty compared to before the intervention (**Paper II**).

The experiences of living with intermittent claudication were studied through qualitative interviews with individuals suffering from peripheral arterial disease. The interviews were analyzed by thematic content analysis and six themes together founded a main theme concerning adjusting to a restricted life when living with intermittent claudication (**Paper III**).

Spouses and cohabitants were interviewed about their experiences of living together with a person suffering from intermittent claudication. The overall theme was about living a demanding life when living together with someone with intermittent claudication. The findings of this study give insight into the complexities and the difficulties of ageing and living together with someone suffering from intermittent claudication (**Paper IV**).

In conclusion, living with intermittent claudication has a major impact on daily life and demands adjustment to a restricted life. Percutaneous transluminal angioplasty improves health related quality of life among individuals suffering from peripheral arterial disease and the effect is sustainable over time up to one year after the intervention. People who had undergone percutaneous transluminal angioplasty were younger in the proximal group and hematomas/bruises were more common among non-diabetic patients. Ageing and intermittent claudication have great impact on both the spouse's and the ill person's life situation.

Keywords: Peripheral Vascular Disease; Experiences; Angioplasty, balloon; Health related quality of life; Life situation; Family members

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LIST OF ABBREVIATIONS

CLAU-S	Claudication Scale
CLI	Critical Limb Ischemia
EQ5D	EuroQol 5 D
HRQoL	Health Related Quality of Life
IC	Intermittent Claudication
PAD	Peripheral Arterial Disease
PTA	Percutaneous Transluminal Angioplasty
SOC	Sense of Coherence

INTRODUCTION

Living with peripheral arterial disease is associated with pain, impaired mobility and loss of control. Both physical and social functions are often negatively affected as well as health related quality of life. Peripheral arterial disease is a chronic disease usually due to arteriosclerosis, leading to narrowing blood vessels with ischemic injury as a result, causing symptoms of intermittent claudication or critical limb ischemia ¹. The life situation is affected for both the ill person and their family members.

With the demographic profile shifting to an aging population it is quite possible that the occurrence of peripheral arterial disease will increase in the future ² since this disease has higher prevalence in old age ³.

Percutaneous transluminal angioplasty (PTA) is a well-established method of treatment for peripheral arterial disease. Previous studies have shown that health related quality of life (HRQoL) was improved by treatment using percutaneous transluminal angioplasty⁴⁻⁹. There is however a lack of research concerning HRQoL in patients with peripheral arterial disease undergoing percutaneous transluminal angioplasty assessed with disease-specific questionnaires¹⁰.

It is important to gain knowledge about how individuals suffering from illness are affected in daily life and how this corresponds to the expectations the person has on life. To understand how quality of life changes when subjected to different treatments and interventions is also essential to understand the ill person's needs.

In my clinical work as a registered nurse I have met a lot of patients suffering from peripheral arterial disease and some of them have undergone percutaneous transluminal angioplasty. During the course of the studies in this thesis I have had the opportunity to learn about the outcomes of the PTA-interventions and how the intervention affected the patient's quality of life. When a person is suffering from chronic illness, the consequences of the diagnosis and the illness itself affect the person as well as their family members. I have had the privilege of listening to both people suffering from peripheral arterial disease and their family members, telling me their stories about the experiences of life with peripheral arterial disease. Since the family members are an essential part of the ill person's life it is of great importance for health care professionals to gain knowledge concerning both the patients' and the family members' situation to be able to understand and treat the patient appropriately.

This thesis is intended to make a contribution to enhance the knowledge and understanding of the life situation among people suffering from peripheral arterial disease as well as the experiences of their family members.

BACKGROUND

LIVING WITH CHRONIC ILLNESS

Living with chronic illness often leads to a more restricted life, loss of control and social isolation¹¹. Both physical and social functions are often negatively affected¹²⁻¹³ and those suffering from chronic illness can also miss their previous life¹⁴⁻¹⁵. Being diagnosed with chronic illness changes the ill person's view of the future¹⁶ and life with chronic illness can give a feeling of being a burden to others¹²⁻¹³.

In order to understand what life with a chronic illness is like it is essential to get the ill person's perspective of daily life with illness. This inside perspective is described by Conrad¹⁷ as a subjective perspective (the ill person's perspective), as opposed to the outside perspective where you see the illness and the patient as a diagnosis or an object. By listening to people's stories, so called "illness narratives"¹⁸⁻¹⁹, we can learn more about what life is like with different illnesses and thereby get an increased understanding for their situation. This increased understanding can in turn improve the treatment of and the respect for the individual.

There is however a risk that an ill person is not taken seriously if the illness cannot be proven medically by, for instance a diagnosis since one can suffer from an illness without having a medically proven disease¹⁹⁻²⁰. Unfortunately many feel they are not taken seriously²¹ or that health care professionals think they know the ill person's needs without even asking and treat them like an object without a will of their own²². To be treated well and to get confirmation from others is important when living with chronic illness just as the opposite can give a feeling of being questioned or of being of less value than before the illness²³.

Life with chronic illness is all about being "a whole person" as opposed to "a patient"²⁴ if the ill person does not allow him/herself to be defined by the disease. This can be described as the subjective (the ill person) experience and the objective (e.g. healthcare) opinion of living with illness²⁵. Healthcare today is often disease oriented and not patient oriented, which may cause problems when patients with the same diagnosis are all treated the same way. This in turn may cause problems for instance when a patient is being discharged from the hospital and after-care is not fully planned and thought through properly²⁴.

An inside perspective of illness should according to Conrad¹⁷ include the ill person's feelings of how the illness has changed them in their own view, but also when seen through other's eyes. It is not unusual that a person with an illness changes in appearance, has a different way of moving and no longer has complete control of the body. This can lead to stigmatization and thereby lead to problems in the relationship with other people²⁶. Regrettably there are many examples of people with illness who feel that those close to them distance themselves or suddenly treat them differently because of the illness^{22, 27-28}. An example could be friends crossing to the other side of the street when you are about to meet on the sidewalk.

Chronic illness is a threat to the ill person's identity¹⁷ and self-image. People with chronic illness can suffer greatly from this loss of self-image because when it is lost it is not replaced by a new, comparable self-image. Instead the ill persons decrease their life activities and sometimes even isolate themselves from the outside world¹¹. To understand what has happened and to get an explanation of the changes caused by the illness can make it easier to incorporate the illness^{21,27} in life and to gain new self-image¹¹.

Chronic illness affects life in different ways depending on if the illness is life threatening or not as well as on how much the symptoms affect the daily life^{17,29}. When someone is suffering from pain or limited ability to move around, the illness is more apparent compared to someone suffering from high blood pressure for instance, where the blood pressure can be kept stable with adequate treatment. When someone is suffering from pain they have to learn how to handle the pain and not identify with it. When a diagnosis is made the illness can be seen in another, more objective way¹⁹.

In order to understand what it is like to live with illness it is important to know how the ill person first noticed that something was wrong and what this meant to them, what explanations they had for what was happening and how they adjusted to this change in life¹⁷. The effects the diagnosis or the illness will have on daily life, the change from life in a family where everyone is healthy to suddenly living with someone suffering from chronic illness, can be a learning process for the entire family^{25,28}.

Many people suffering from chronic illness are not entirely independent; they may need daily assistance from others. It's important for these people to receive help and to surround themselves with people they trust²⁷. Apart from the direct effects of the illness the ill person and their family members often have to struggle to manage all of the practical things in life. For instance, keeping track of and fitting in visits to doctors into the daily routine, arranging transportation, getting home-help service to work satisfactorily and so on, things that take a lot of their time. Often the ill person has to visit several different specialists that many times only see their specialized part and not the big picture, the entire scope of the person's illnesses²⁴. For family members this could mean putting oneself in second place to be able to support the ill person or to support other relatives or friends when worried about how they are affected by the situation³⁰.

The relationship between family members and the chronically ill person is affected in many ways. The family members and the consequences the disease has on their lives also require attention^{14,31}. A deeper understanding of life with chronic illness and of how both the ill person and their family members are affected by the illness is needed in order for healthcare to develop and to treat those with chronic illness in a better way²⁴. One way to gain deeper understanding is to pay attention to peoples' stories of their life with chronic illness¹⁷.

PERIPHERAL ARTERIAL DISEASE

Epidemiology

Peripheral arterial disease (PAD) is a chronic disease usually due to arteriosclerosis where the plaques lead to a narrowing lumen in the blood vessels (stenosis or occlusions). This causes obstruction of the of blood flow to peripheral tissues leading to ischemic injury ¹. Peripheral arterial disease also indicates a more general arteriosclerosis and it is not unusual that people with PAD have coronary insufficiency or cerebrovascular disease. Persons afflicted by PAD are more likely to die from cardiovascular disease, e.g. myocardial infarction or stroke, compared to healthy people of the same age ^{3,32}.

It is difficult to compare or transfer findings of different studies about incidence and prevalence of PAD to other populations since different symptoms, age groups or geographic areas can be assessed. Sometimes all cases may not have been recorded and consequently the prevalence may be even higher. According to existing studies the prevalence of intermittent claudication in a Swedish population aged between 60-90 years was 6.8% in a recent study ³³. In an earlier study the prevalence of PAD in a Swedish population was 4.1 % in the age range 50-89 years, which translates into approximately 2 % of the total population ³⁴. The prevalence of PAD in an American community was 3 % in the age range 40-59 years, 8 % at 60-69 years and 19 % \geq 70 years ³⁵.

Risk factors for arteriosclerosis apart from age are tobacco smoking ³⁶⁻³⁷, diabetes, hypertension and hyperlipidemia ³⁷. Peripheral arterial disease is equally prevalent among men and women ³⁸⁻⁴⁰. Women have a higher prevalence than men of asymptomatic PAD diagnosed with ankle-brachial index ⁴¹ and because of the similar risk of vascular morbidity and mortality in asymptomatic PAD, it is important to screen women for PAD ⁴². It is well known that PAD increases with age ⁴³, as in the case with other chronic diseases and infirmities where occurrence peaks at 65 years and over ⁴⁴.

Symptoms

PAD can be asymptomatic or become manifest as intermittent claudication or critical limb ischemia ¹. The clinical classification of PAD is most often made by using Fontaine's stages or Rutherford's categories, see table 1 ³². One characteristic feature of PAD is reduced walking ability or intermittent claudication caused by lower limb ischemia ⁴⁵. The symptom intermittent claudication is cramping or aching in the leg while walking, which is relieved by a short rest ¹ and is the earliest and most frequent symptom in people with lower extremity PAD. Pain while walking could be assumed to be a part of the natural ageing process and the lack of knowledge about PAD in the general public delays the seeking of medical help ¹². Critical limb ischemia is a more severe manifestation of PAD and is defined by the symptoms of rest pain, necrosis and gangrene ¹.

Table 1. Fontaine's stages and Rutherford's categories of peripheral arterial disease ³².

Fontaine		Rutherford		
Stage	Clinical	Grade	Category	Clinical
I	Asymptomatic	0	0	Asymptomatic
IIa	Mild claudication	I	1	Mild claudication
IIb	Moderate to severe claudication	I	2	Moderate claudication
		I	3	Severe claudication
III	Ischemic rest pain	II	4	Ischemic rest pain
		III	5	Minor tissue loss
IV	Ulceration or gangrene	III	6	Major tissue loss

Diagnostic procedure

Ankle Brachial Index (ABI) is used for diagnosis of PAD with a value lower than 0.9 being accepted as diagnostic ⁴⁶. ABI is used when assessing the lower extremity arterial perfusion and is a noninvasive diagnostic test ⁴². To measure ABI the highest systolic ankle pressure is divided by the systolic brachial pressure ^{32,47}. There are however differences in recommendation concerning how to measure ABI, using the highest or lowest or the mean systolic pressure of the two ankle arteries ². False high ABI can however be obtained if the arteries are heavily calcified and incompressible at the malleolar level. This is common among people suffering from diabetes and can lead to an underestimation of the severity of the disease ⁴⁷.

The WHO/Rose Questionnaire was developed in 1962 by G A Rose to diagnose intermittent claudication in field surveys ⁴⁸. From the WHO/Rose Questionnaire the Edinburgh Claudication Questionnaire has been constructed to detect intermittent claudication, this corresponded well to the doctors' diagnosis when evaluated ⁴⁹. However detection of PAD among people with diabetes with the Edinburgh Claudication Questionnaire was low compared to a diagnosis based on ABI ⁵⁰. When assessing only with questionnaires there is a risk of overestimating the occurrence of PAD since other symptoms similar to those of PAD can come into account ⁴³. Comorbidities such as spinal stenosis or neuropathy for example can sometimes be confused with PAD ⁴⁵. The source of pain can be hard to distinguish and opposite to what is stated above this can result in an underestimated prevalence ⁵¹.

PERIPHERAL ARTERIAL DISEASE AS AN ILLNESS

Living with peripheral arterial disease

Living with PAD is associated with pain, impaired mobility and loss of control⁵² and both physical and social functions are often negatively affected¹². The impaired walking ability leads to major limitations in daily life⁵³ and a decreased quality of life³, and people suffering from PAD are often concerned about the reduction in their walking ability^{12-13, 54}. Due to the effects of the decreased functional capacity people suffering from PAD sometimes require both support from other people as well as physical support like the use of a walking cane which is sometimes seen as embarrassing⁵⁵.

Many are concerned about the reoccurring pain⁵³, worried about possible future amputation^{12-13, 54} and those amputated can be afraid of falling, worried about getting phantom pains and the increased dependency on others⁵⁶. The reduced walking ability in turn leads to increased isolation because the person tends to be less active in leisure activities as well as other social activities^{12-13, 54-55}. Help from friends or family members is needed and this could give a feeling of being a burden to others¹³ and loss of independence⁵⁵. Intermittent claudication is also associated with psychological factors such as impaired mood⁵⁷.

It is well known that PAD increases with age³ but pain while walking could be assumed to be a part of the natural ageing process, this and the lack of knowledge about PAD in the general public delays the seeking of medical help¹². Effective treatment methods in the form of medication and/or surgical interventions with open or endovascular methods such as bypass surgery or percutaneous transluminal angioplasty (PTA) can ease the symptoms and to a certain extent stop the progress of the disease, but is not curative⁵⁸. Increased knowledge concerning the experience of living with illness from the insider's perspective is needed¹⁷ to deepen the understanding of people living with PAD and to be able to improve their treatment.

Health related quality of life

Measuring health-related quality of life (HRQoL) has become increasingly important in evaluating people with PAD, both to understand the impact of the illness and to capture information regarding medical and nursing interventions. Functional status in intermittent claudication is assessed with objective measures like treadmill testing where the walking ability is determined by measuring time and/or distance of walking until onset of claudication and time and/or distance to termination of walking due to leg pain⁵⁹. This kind of measurement or functional status questionnaires like the Walking Impairment Questionnaire⁶⁰ or a health status questionnaire like the Peripheral Artery Questionnaire⁶¹ do not however address to the individual's perception of their situation or their HRQoL⁶². Health related quality of life can be defined as a reflection of a person's mental, physical and social beliefs and perceptions in relation to health and rests upon a concept of health as well as a concept of quality of life⁶³.

Health related quality of life is negatively affected by PAD, according to previous studies, due to fatigue, reduced mobility and pain⁶⁴⁻⁶⁸. The person's daily living is affected due to symptoms such as pain and decreased ability to walk. The feelings of loss of independence and isolation are often related to reduced physical mobility^{12-13, 52-53}. The pain often interferes with sleep and some people even have to sleep sitting with the legs down on the floor due to the severe pain⁵³. The use of strong analgesics to reduce the pain can result in constipation and nausea that also affect the quality of life⁶⁹.

Health related quality of life can be assessed with generic as well as disease-specific instruments⁶³.

Assessing health related quality of life with generic instruments

Several studies have measured HRQoL over time in people with PAD with different kinds of generic instruments, applicable across populations irrespective of health conditions such as: EQ5D, Nottingham health profile and the SF-36 questionnaire⁴⁻⁹. These studies have shown that the HRQoL increased in patients undergoing PTA by improving physical and psychological health and alleviating pain. Remes et al⁶⁸ compared HRQoL among patients who had undergone PTA or other vascular interventions to an age and gender matched control-group using the 15D HRQoL scale. People with PAD had an estimated lower HRQoL in all 15 dimensions of the questionnaire compared to the control-group who did not (as far as they knew) suffer from PAD⁶⁸. The relationship between mortality and HRQoL in people with PAD has been assessed using the EQ5D indicating a relationship between poor HRQoL and mortality⁷⁰.

Assessing health related quality of life with disease-specific instruments

To be able to properly understand how a certain disease and its' symptoms affect the health related quality of life a disease-specific instrument should be used. Disease-specific questionnaires have been developed to assess health related quality of life in people suffering from symptomatic peripheral arterial disease. One of them is the Claudication-scale or CLAU-S, first developed in Germany⁷¹⁻⁷² to examine the effect of a vasodilator (naftidrofuryl) on intermittent claudication. The CLAU-S includes five dimensions: every day life, pain, social life, illness-specific fears and psychological wellbeing. Other PAD disease-specific instruments are the Peripheral Artery Occlusive Disease 86 questionnaire or PAVK-86⁷³, the Vascular Quality of Life questionnaire or VascuQoL⁷⁴ and the Intermittent Claudication Questionnaire or ICQ⁷⁵. Mays et al⁶² suggest it is important to assess HRQoL and functional status in different clinical areas as well as in research as it may be of help in treatment decisions.

Influence on family members

The family members have to face the same symptoms and anxiety as the person diagnosed with PAD, often tying them to their homes, which results in a sense of isolation⁵⁵. Roles in the family often change radically and the family members are burdened with a heavier workload and reduced opportunities for recreational

activities^{14, 55, 76}. Family members need to take one day at a time to be able to cope with the ill person's infirmity⁷⁷. The family members also worry about the progression of the disease in general and the possibility of future amputation in particular since that could increase their already heavy burden. They also express that they feel powerless regarding their lack of ability to do anything to help the person suffering from PAD⁵⁵.

SENSE OF COHERENCE

The salutogenic model, focusing on health instead of disease was formulated by A. Antonovsky when he, after seeing the results of a study, wondered why such a large part of the women in the study (29%) stayed healthy despite their experiences of world war two concentration camps. His conclusion was that people have different general resistance resources (GRR) such as ego, money, cultural stability, coping strategies and social support to handle the different stressors one is exposed to in life. Common to all GRR is that they make the stressors comprehensible. The ability of people's understanding, managing and finding meaning in different situations led to the development of the concept sense of coherence⁷⁸. A standardized questionnaire was constructed to assess sense of coherence, which is a 29-item scale called The Sense of Coherence Scale (SOC) consisting of three dimensions: perceived comprehensibility, manageability and meaningfulness⁷⁹.

A high sense of coherence predicts successful stress management and previous studies have shown a relation between high sense of coherence and better quality of life and wellbeing^{7, 80-81}. Klevesgård et al⁷ illuminate the importance of SOC in a study with people suffering from varying degrees of lower limb ischemia where a higher SOC and ABI were associated with improvements of quality of life.

PERCUTANEOUS TRANSLUMINAL ANGIOPLASTY

Percutaneous transluminal angioplasty with or without stenting is an endovascular treatment method for peripheral arterial disease and is performed in the angiography laboratory under fluoroscopy under local anesthesia. A catheter with a rigid balloon is passed into the artery (with stenosis or occlusion) and inflation of the balloon dilates the blood vessel, which will improve flow. Percutaneous transluminal angioplasty is a well-established method of treatment for peripheral arterial disease⁸². The first successful intervention was performed and presented in 1964 by C. Dotter and M. Judkins⁸³ and was at first used for the treatment of short stenosis of vessels proximal to the inguinal ligament. The development of technologies and instruments (e.g. development of stents, improved catheter and guide wire design) has improved and increased the use of the interventions⁸² and PTA is now even used as treatment in long-segment occlusions distal to the inguinal ligament³².

If the guide wire cannot pass through the occlusion, for example in a completely occluded vessel or long segment occlusion, the technique of subintimal angioplasty can be used as described by A. Bolia and colleagues⁸⁴. This means the angioplasty balloon is manipulated into the subintimal plane at the outset of the occlusion and after it has passed the occlusion it is manipulated back into the lumen again below the occlusion.

The balloon is inflated and a subintimal passage has been established ⁸⁴ with a technical success rate of 91.4 % in a recent study ⁸⁵.

Percutaneous transluminal angioplasty is less invasive than bypass surgery and is also associated with lower mortality and less risk of major morbidity. Compared to bypass surgery PTA also shortens the time needed to be able to return to normal activities ³². PTA can be used as a first course of treatment or as a complement to other types of surgery. Short-term outcomes at six months show a limb salvage rate of 97% ⁸⁶ and in a one-year follow-up study none of the 78 patients required amputation ⁸⁷. Long-term follow up at seven years shows a limb salvage rate of 93% ⁸⁸. There are no differences in duration of patency between men and women regarding outcomes after PTA ⁸⁹. A major significant risk factor for adverse outcome after PTA-intervention is smoking history ⁸⁸.

RATIONALE

Life with peripheral arterial disease and the resulting impaired walking ability leads to major limitations in daily life and a decreased quality of life.

In order to understand what living with peripheral arterial disease is like it is essential to get the ill person's perspective of daily life with illness. One way to gain deeper understanding is to pay attention to peoples' stories of their life and their experiences of living with peripheral arterial disease. This insider's perspective and knowledge concerning both the illness and the disease is needed to be able to understand the ill person's needs and to improve their treatment.

The relationship between family members is affected in many ways when a person is stricken by chronic illness. The consequences peripheral arterial disease have on the lives of those close to the ill person also require attention. A deeper understanding of life with chronic illness and of how both the ill person and their family members are affected by the illness is needed in order for healthcare providers to develop and to treat those with chronic illness in a better way.

Peripheral arterial disease can be treated with percutaneous transluminal angioplasty, which is a well-established endovascular treatment method. To be able to evaluate the intervention it is important to describe the outcomes and also to find out how this treatment affects the health related quality of life. For a proper understanding of this a disease-specific instrument should be used. There is however a lack of research concerning HRQoL in patients with peripheral arterial disease undergoing PTA assessed with disease-specific questionnaires. This gap needs to be addressed in order to obtain increased knowledge of how specific domains of HRQoL are affected in order to be able to better develop the care of this particular patient group.

AIMS OF THE THESIS

The overall aim of this thesis is to generate understanding about the life situation among people living with peripheral arterial disease and their family members. The specific aims were:

- I. to describe the characteristics of all patients who have undergone PTA at a University Hospital in Sweden between 1998 and 2002 and to describe the outcomes of interventions proximal and distal to the inguinal ligament.
- II. to investigate HRQoL over time in patients with PAD undergoing PTA.
- III. to describe individuals' experiences of living with intermittent claudication due to peripheral arterial disease from an insider's perspective.
- IV. to describe family members' experiences of living with a person suffering from intermittent claudication caused by peripheral arterial disease.

METHODS

Table 2. Overview of the methods in Paper I-IV.

	Paper I	Paper II	Paper III	Paper IV
Design	Retrospective descriptive	Prospective longitudinal	Qualitative descriptive	Qualitative descriptive
Participants	188 patients (77 men and 111 women)	41 patients (21 men and 20 women)	15 individuals suffering from intermittent claudication (8 men and 7 women)	10 spouses (3 men and 7 women)
Inclusion criteria	All patients undergoing PTA between 1998-2002	Patient schedule for PTA	People living with intermittent claudication	Cohabitant with a person living with intermittent claudication
Age, mean	Mean age 71±10.1 years, range 40-90 years	Mean age 68 years, range 47-87 years	Mean age 73 years, range 64-81 years	Age range 65-79 years
Data collection	Chart review: A study-specific protocol	Questionnaire: CLAU-S, EQ5D, SOC	Qualitative interviews	Qualitative interviews
Analysis	Descriptive, The Pearson Chi-square test and t-test	Descriptive Mann-Whitney test, pair wise t-test and Kruskal-Wallis	Qualitative thematic analysis	Qualitative thematic analysis

Abbreviations: CLAU-S = Claudication scale, EQ5D = EuroQol questionnaire, SOC = Sense of Coherence scale.

DESIGN

The collection of data through patient records, questionnaires and qualitative interviews provides a broad understanding of the life situation among people living with peripheral arterial disease, those going through PTA-interventions, as well as their family members.

A retrospective descriptive design was chosen for Paper I where the data was collected by reviewing patient records to obtain knowledge about the outcomes after PTA-interventions.

To be able to follow up and gain knowledge about people's health related quality of life after PTA-interventions a prospective longitudinal design was used in Paper II. There was no control-group; the aim of the study was to scrutinize the patients' health related

quality of life over time and not to compare this with other groups. The use of a generic questionnaire (EQ5D) facilitates the comparison with other studies (even involving other diseases) using the same questionnaire.

Qualitative thematic analysis was applied in Paper III-IV. The data giving the insider's perspective of the experiences of living with intermittent claudication (Paper III) and the experiences of living together with someone suffering from intermittent claudication (Paper IV) were collected through qualitative interviews.

SAMPLE AND PROCEDURE

Participants

A total of 254 (Paper I n=188; Paper II n=56, 41 completed; Paper III n= 15; Paper IV n=10) people living with peripheral arterial disease and spouses living with people suffering from intermittent claudication were included in the different studies in this thesis. One person included in Paper II, also participated in Paper III.

All patients treated with PTA due to PAD at a University Hospital in Sweden between January 1st 1998 and December 31st 2002 were included in Paper I. The samples for Paper II-IV were recruited from another University Hospital in Sweden between December 2005 and June 2007 (Paper II) and between November 2009 and June 2010 (Paper III-IV). The inclusion criteria in Paper II were patients with PAD who were scheduled for PTA (with or without stenting) and acceptance for participation. The inclusion criteria in Paper III were people diagnosed with intermittent claudication due to PAD and listed for visits/revisits to the vascular surgery department. In Paper IV the inclusion criterion was cohabitant (spouses) to a person diagnosed with peripheral arterial disease, suffering from intermittent claudication. Exclusion criterion in Paper II-IV was not speaking or understanding the Swedish language.

The catchment area of the hospital in Paper I covered a mainly urban population of 450 000 people. In Paper II-IV the hospital's catchment area covered a population of 800 000 people. The sample technique for Paper III-IV was purposive sampling to select a sample with a wide range of duration of their intermittent claudication symptoms, both men and women of different ages and to get information-rich cases⁹⁰.

Drop-outs

Out of the 56 participants included in Paper II, 47 patients participated at the one-month follow-up and 41 patients completed the one-year follow-up. Out of the fifteen participants who were lost to follow-up: eight did not wish to participate any longer, three had developed other serious diseases, one had died and three could not be located.

Data collection and procedure

In Paper I the data were extracted verbatim from the patients' medical and nursing records from surgical, medical, orthopedic and geriatric clinics at the hospital and all

data was collected by the same person (L.E.). In order to identify the sample and for data collection (e.g. anatomic treatment location, revascularizations and re-operations), the nationwide registry of vascular and endovascular surgery in Sweden, Swedvasc, was used by permission from its Board. Only the first endovascular intervention (PTA) per patient during the period was included. Procedures after the included PTA-intervention on the same leg were referred to as “re-PTA/re-operation” and any vascular/endovascular operations prior to the study period were termed “previous operations”.

Medical and nursing records were reviewed to obtain demographic and medical characteristics in Paper II, e.g. age, gender, smoking habits, diseases relevant to peripheral arterial disease (e.g. stroke, hypertension, myocardial infarction and diabetes) and complications after the vascular treatment (e.g. hematoma at the puncture site) repeated revascularizations, reoperations of the same leg and amputation. Data for health related quality of life were collected by two different questionnaires, CLAU-S and EQ5D and the sense of coherence by the Sense of Coherence scale, SOC. All three questionnaires were distributed to the participant at the hospital the same day or the day after the intervention (baseline). Follow-up was carried out one month and one year after PTA-intervention, the questionnaires (CLAU-S and EQ5D) were then sent by mail to the participants. The Individual National Registration Records were checked to see whether the participants were still alive at either follow-up prior to mailing.

Twenty-five interviews were carried out (15 in Paper III and 10 in Paper IV) during winter and spring 2009-2010. The purpose of the qualitative interviews was to gather as much information as possible with focus on the content of the interview and to interview enough people to capture the variations of different experiences of the same phenomena. This is more dependent on the skills of the inquirer and the depths of the interviews rather than sample size⁹⁰. There are no strict rules as to the number of participants in a qualitative study. According to Kvale and Brinkmann⁹¹ the size of the sample should be between 5-25 people. All interviews were conducted by the same person (L.E.), in the participant’s home (n=19), in a room at the author’s working place (n=4), in a room at the hospital (n=1) and by telephone (n=1) according to the participant’s preference. The interviews were all audio recorded and lasted approximately 40-100 minutes, transcribed verbatim and then carefully compared to the original recordings to assure no words or sentences were written incorrectly and thereby influencing the interpretation later on.

Questionnaires

Study specific protocol

A study specific protocol was developed (Paper I) based on scientific literature issues and clinical experience of two vascular surgeons and a registered nurse (L.E.) experienced in the care of vascular patients. Scientific papers and textbooks concerning PAD and PTA were reviewed in order to gain deeper knowledge about diagnoses, symptoms, living with PAD, conservative-, medical- and surgical treatments placing emphasis on PTA-procedures and outcomes. The variables included in the protocol

were continuously questioned and confirmed by discussions within the research group during the development and then tested on randomly selected patient records. The protocol finally included: age, gender, legal and social status, home help service, anatomic treatment location (distal or proximal to the inguinal ligament), smoking history, co-morbidities (e.g. diabetes, myocardial infarction, stroke and hypertension), ulcers, pain before and after the revascularization, complications after the intervention such as hematoma at the puncture site, re-operations or revascularizations of the same vessel, amputations and survival rate.

The questionnaires in Paper II were the Claudication scale, EuroQol 5D and the Sense of Coherence scale.

Claudication scale (CLAU-S)

CLAU-S is a peripheral arterial disease specific instrument, first developed in Germany⁷¹⁻⁷². The questionnaire includes 47 items grouped in 5 dimensions:

1. Every day life. How do you manage in every day life?
2. Pain. How frequent and how severe is the pain in the affected leg?
3. Social life. What impact does the illness have on the relationship with others?
4. Illness-specific fears, the psychological affect of the illness.
5. Psychological wellbeing, referring to mood.

CLAU-S was translated into Swedish following the guidelines for forward-backward translation⁹² prior to being used in this study. The translated version was then translated back into the source language in order to verify the translation⁹³. Twenty persons suffering from peripheral arterial disease tested the questionnaire in order to obtain the linguistic validation. Cronbach's alpha coefficient was calculated for the five dimensions (Table 3).

Table 3. Cronbach's alpha coefficient calculated for the five CLAU-s dimensions

Dimension	Items	Cronbach's alpha Swedish version	Cronbach's alpha English version
Daily life	9	0.90	0.90
Pain	10	0.74	0.74
Social life	4	0.80	0.73
Illness-specific fears	13	0.67	0.91
Psychological well being	11	0.90	0.89

EuroQol 5D (EQ5D)

EQ5D, a generic instrument, was used to assess the seriousness of conditions at different times (baseline, one-month follow-up and one-year follow-up). EQ5D defines health in five dimensions: mobility, self-care, pain/discomfort, usual activities and anxiety/depression. Each of the five dimensions has three response categories corresponding to 'no problem', 'some problem' and 'extreme problem'. EQ5D also includes a self-rating of health status on a visual analog scale (VAS), called EQ VAS.

It is a quantitative measure, illustrated as a 20-centimeter vertical VAS, where the endpoints are 0 for ‘worst imaginable health state’ and 100 for ‘best imaginable health state’,⁹⁴⁻⁹⁶.

Sense of Coherence scale (SOC)

The SOC short version (13 items), developed from the original 29-item scale, was used to estimate the patients’ sense of coherence⁸⁰. The scale consists of three dimensions: Perceived comprehensibility (five items), Manageability (four items) and Meaningfulness (four items) and has a 7-point Likert-scale format, ranging from ‘never’ to ‘very often’. The total range of the scale is 13-91 points. The scale is regarded as valid and reliable⁹⁷ and can be separated into three groups: low (30-60 points), moderate (61-75 points) and high (76-91 points) sense of coherence⁹⁸.

Qualitative interviews

The purpose of the qualitative interviews conducted in Paper III and IV was to gain rich and deep data about the experiences of living with intermittent claudication (cf Patton, 2002) and to focus on the insider’s perspective as described by both the ill person and the spouse^{11, 17}. The core of qualitative inquiry is the understanding of phenomena from different perspectives, inside or outside, and interviewing is one of the most common methods of data collection within qualitative studies. To understand the insider’s perspective, the interview provides opportunities to find out what other people have in and on their minds, like feelings or thoughts, that can not be observed from the outside or captured through questionnaires⁹⁰.

The interview method used in Paper III and IV was what Patton⁹⁰ calls the general interview guide approach, or what Kvale and Brinkmann⁹¹ calls the semi-structured interview. An interview guide is then used to assure certain topics are covered in the interviews, in this case pain, mobility, daily life and social life (friends, family etc.). The interviewer is however free to shape the phrasing or order of the questions⁹⁰⁻⁹¹. Before the interview started, the aim of the study was again stated and the audio recording system was tested with a question about today’s date. The interviews then started with the question: “Please, tell me about your experiences of living with reduced circulation in the legs” (Paper III) or “Please, tell me about your experiences of living with someone with reduced circulation in the legs” (Paper IV). Participants were invited to talk openly about their experiences of living with intermittent claudication (Paper III) or about their experiences of living with a person suffering from intermittent claudication (Paper IV). Follow-up questions were asked to clarify or deepen the answers⁹¹. We strove to ask the questions in a clear, neutral and singular way since the participant’s responses are affected by how the question is worded⁹⁰. Open-ended questions were used in the interviews. According to Patton⁹⁰ the interviewees were then able to respond in their own words and predetermined answers were avoided.

DATA ANALYSIS

STATISTICAL ANALYSIS

Table 4. Overview of statistical methods

	Paper I	Paper II
Chi-square	X	
T-test	X	X
Mann-Whitney		X
Kruskal-Wallis		X

In Paper I the variables were converted into numerical data. As none of the variables, with the exception of age, fulfilled the assumption of normal distribution, non-parametric methods were used. The Pearson Chi-square test was used to test the differences between two independent groups of nominal-level data. For age, the Student's t-test was used.

Repeated measurements analysis was used in Paper II to analyze time dependent data and statistical comparisons to test differences between two groups were made by use of the Mann-Whitney test. The global score and dimension scores of CLAU-S were adjusted to range from 0 (bad) to 100 (good health related quality of life). The Mann-Whitney test was then used to test the ordinal data from CLAU-S and the EQVAS. The EQ5D scores were computed by index⁹⁹ and pair-wise t-tests were used to analyze the differences in health related quality of life over time. The Kruskal-Wallis test¹⁰⁰⁻¹⁰¹ was used to test the differences between the groups of SOC scores regarding the CLAU-S scores over time.

All analyses were carried out by use of the Statistical Package for the Social Sciences, version 14.0 in Paper I and version 16.0 in Paper II (SPSS Inc., Chicago, IL, USA). The 5% level of significance was considered as statistically significant in Paper II and P-values ≤ 0.01 were considered as statistically significant in Paper I regarding mass significance.

QUALITATIVE CONTENT ANALYSIS

The aim of qualitative content analysis is to focus on the individuals' experiences. The method can be described as a process of detailed and systematic identifying, coding and categorization of patterns in data and in some cases interpreting them into themes⁹⁰. Published scientific papers using qualitative content analysis as a keyword have greatly increased during the 21st century¹⁰². In analyzing interview transcripts it is essential to be systematic^{90-91, 103} and since guidelines on qualitative content analysis require judgment and creativity the analyses are dependent on the skills of the inquirer⁹⁰.

In Paper III and IV qualitative thematic analysis was used as described by Patton⁹⁰. The analysis was carried out in two steps: first in a more descriptive phase where the experiences of living with intermittent claudication (Paper III) and the experiences of living with a person suffering from intermittent claudication were made (Paper IV) and then a second conclusive interpretive phase. The findings are presented in a different order in the manuscripts, where the interpretations come first followed by the descriptive part, which is close to the original text.

Directly after each interview spontaneous first reflections were noted and proper functioning of the audio recording was checked. This is where analysis and interpretation starts according to Patton⁹⁰ and insights of the data can emerge that otherwise can be lost. This phase is important to promote rigor of qualitative inquiry. The interviews were transcribed verbatim and the transcriptions were then carefully compared to the original recordings. All interviews were first read to understand the overall meaning and thereafter read several times while the data was analyzed searching for patterns. With the aim of the study in mind, notes regarding the content were made in the margins.

During the first phase of analysis, key phrases that are collections of words, sentences or paragraphs carrying a meaning of importance for the study, were identified and coded in a systematic way. Two interviews in Paper III and three interviews in Paper IV were first read and coded independently by all three authors. Thereafter coding was discussed leading to consensus, before the remaining interviews were coded. The data was structured in the OpenCode software¹⁰⁴ during the analysis process. New codes were constructed, others changed, renamed or merged together before the coding was completed and categories could be structured by grouping codes dealing with the same content together.

These descriptive findings were then the foundation for the second interpretive phase of the analysis. This is when data was compared forward and backward between the whole and parts of the transcriptions, back and forth between data and the inquirers' own perspective; categories to codes and back to categories again, while interpreting to themes. Conclusions were drawn and six different themes in Paper III together founded one main theme. In Paper IV thirteen subthemes were grouped into four different themes and one over-all theme emerged from the over-all findings.

Representative quotations were selected to illustrate the findings in Paper III-IV and according to Sandelowski¹⁰⁵ the selection of quotations should be faithful to what the participant wanted to say and to the researcher's idea of the meaning of the quote. We made some minor linguistic and grammatical changes, since spoken language in writing can be difficult to read and understand^{91, 105} and sometimes even make the interviewees sound foolish.

METHODOLOGICAL CONSIDERATIONS

One important aspect of research is the ability to judge the accuracy of research findings. For this reason we strove to carefully describe the research process, including all the different steps, as detailed as possible in Paper I-IV. Strengths as well as limitations of the four papers included in this thesis are reflected upon in the text below.

Design

Different methods are needed to research different aspects of a phenomenon¹⁰⁶. One of the strengths of this thesis is the use of different designs. We measure the different outcomes and health related quality of life among people going through PTA-interventions by chart review and questionnaires (Paper I-II) and by interviewing people about their experiences we deepen the understanding of living with intermittent claudication as well as the spouses' experiences of living with someone suffering from intermittent claudication (Paper III-IV).

Inclusion

The limitation of a sample through inclusion and exclusion criteria might lead to a different understanding and description of the quality of life or the experience of living with illness and of going through certain interventions. Ideally everybody should be included and no one should be excluded if one really wants to find out how quality of life is influenced or how living with chronic illness is experienced. Even those living with the illness but not yet diagnosed should be included²⁹. The inclusion criterion in Paper II was people diagnosed with peripheral arterial disease and in Paper III-IV people suffering from intermittent claudication. People who did not speak or understand the Swedish language were excluded in Paper II-IV. The implications of this can be discussed. However, it can be difficult in practice to conduct interviews without a mutual language or to locate people, not yet diagnosed, living with the illness²⁹.

At the planning stage the sample in Paper II was designed to be consecutively included. According to logistic problems due to reorganization and centralization of the vascular surgery unit we had to include participants when given opportunity. The inclusion of participants came to an end one and a half year later. The fact that the inclusions were not controlled might affect the external validity. In the sample the range of age was 47-87 years and sex was equally divided (21 men, 20 women). The majority had symptoms classified as intermittent claudication (85%). Only 15% had symptoms classified as critical limb ischemia. Whether this was the normal distribution of these two groups in PTA-interventions overall at the hospital was not inquired in this paper and should be taken into account.

The participants in Paper III were chosen to include various ages and both sexes as well as various lengths of the experience of living with intermittent claudication. Thus broadening the descriptions of the phenomenon and thereby giving credibility to the study⁹⁰. The age of the participants varied between 64 and 81 years, all but one of them

were retired. This should be taken into account concerning the transferability of the results⁹⁰.

Asking participants from one study (Paper III) for permission to include their family members in another study (the sample of Paper IV) might be seen as a way of convenience sampling⁹⁰. There was however a broad range in age and both women and men were included and all in all they gave a rich description of the experiences of living with someone suffering from intermittent claudication. The result is an opportunity to view two different sides of a joint life with intermittent claudication.

Data collection

One strength when developing the protocol of Paper I was the clinical experience of taking care of patients going through PTA-interventions. This experience together with issues based on scientific literature were included in effort to strive to avoid overlooking any variable. One ambition of Paper I was to describe the nursing care of patients going through PTA-interventions. Nursing variables such as pain, ulcers and home help service included in the protocol were not included in the results because documentation concerning these variables was rarely present in the patient records. Although these variables were checked for availability in random patient records during the protocol development, it may be that the assessed records were not representative as the variables were rarely found in the study sample records.

Questionnaires

When testing the questionnaire in Paper II the response rate of one question under the dimension "illness specific fears" were low because people who did not have a partner found it hard to answer the questions with the alternatives given. The question was "How worried or afraid were you in the past week about your partner turning away from you?" One new alternative answer to this question was added ("not relevant") to prevent having questions unanswered. Original response alternatives were: not at all, somewhat, moderately, quite a bit, very much. In the analysis the answer "Not relevant" was converted to "Not at all" since in this case there was no worry that the partner would turn away.

Interviews

The participants chose the place and time for the interviews in Paper III-IV and most of the interviews were carried out in the participants' homes in familiar and relaxed surroundings. To ensure that stress was not an issue that could have affected the interview, there was no time limit. Whether the interviews were carried out in the participants home or in a room at the author's working place or at the hospital it was carried out in a quiet, undisturbed setting as Kvale and Brinkmann⁹¹ recommends. During two of the interviews in the participants' homes a family member entered the room interrupting the interview. This could have influenced the findings since it took a while to come back to the interview and follow-up questions were missed in one of these interviews.

The interviews differed from each other both regarding the way the interviewees expressed themselves and how long the different interviews lasted. Regardless of these variations the interviews all together gave a rich description of the experiences of living with intermittent claudication.

Analysis

Regarding the accuracy of data in Paper I, errors may have occurred at three different stages. First during examinations of the patients and second during documentation in the patient records made by the nurses/surgeons. Thirdly this could also have happened later, during the collection and interpretation of data¹⁰⁷. Since the same person took part in the development of the protocol as well as carried out the data collection there was a risk of the pre-understanding affecting what data would be found. In an attempt to avoid this, the records were thoroughly examined. The fact that only one person carried out all the data collection can also be seen as strength since data were not interpreted differently and handled equally.

In Paper III-IV, all authors first read and coded some of the interviews independently; a form of analytical triangulation, various ways of scrutinizing the data can provide important understandings⁹⁰. This was followed by a discussion leading to common understanding and agreement of the coding. This contributed to increase trustworthiness. The categories were judged both by internal homogeneity and external heterogeneity to strive for their independence⁹⁰.

The experiences of living with intermittent claudication and living together with someone suffering from intermittent claudication are described close to the original wording of the interviews in the descriptive part of Paper III-IV. This gives the readers a chance to make their own interpretation even though we strove to present the most probable interpretation¹⁰⁸. Representative quotations were selected to illustrate the findings in Paper III-IV and to gain credibility¹⁰⁸.

ETHICAL CONSIDERATIONS

The foundation of research ethics is based on the researcher's own ethical responsibility to make sure the research is morally acceptable and of good quality. The researcher's professional work ethics must also be respected (CODEX the Swedish Research Council website)¹⁰⁹. The studies included in this thesis are approved by The Karolinska Institutet Ethics Committee North (Dnr 03-012, 03-803) and The Regional Ethical Review Boards (2008/1510-31, 2005/52-31).

Ethical consideration concerning the participants in the studies follow the International Council of Nurses Codes of Ethics for Nurses (ICN, 2005)¹¹⁰ and the principles of the World Medical Association Declaration of Helsinki (Oct 2008)¹¹¹. These ethical principles include paying attention to the potential risk of violating human dignity, integrity, the right to self-determination, privacy, confidentiality and also the researcher's responsibility towards employers and sponsors and are discussed in the text below.

The participants in Paper II-IV were guaranteed confidentiality and informed that their participation was voluntary and that they had the option to withdraw at any time without giving a reason. They all gave their informed consent to participate in the study. The participants were free to decide where the interviews took place. With permission from the participants the interviews in Paper III-IV were audio recorded. The participants approved the use of quotations from the interviews to illustrate the findings and they were also informed that data would only be published on a group level. In Paper I the scope of the approval by the Ethics Committee permitted data collection from patient records.

The issue regarding dependency relationship always has to be considered when asking for participation in a study. This issue could have been raised in Paper II since a nurse working on the vascular surgery ward assisted in the inclusion of the participants. The nurse was however not involved in the study in any other way. In Paper III-IV the participants were asked for participation by the interviewer (L.E.), not involved in their care or treatment.

The study specific protocols (Paper I), the questionnaires (Paper II) and the interview transcriptions (Paper III-IV) were coded and the codelists were kept safe as well as the data-storage containing all interviews. All personal matters were treated confidentially. No names or other conceivable personal data that could expose the participants' identities were used in the transcriptions or during the analysis. In order to keep track of the recordings the interviews were named by the date of the recording (expressed when testing the audio recording equipment).

When interviewing people about their experiences, ethical dilemmas may sometimes arise if the questions are seen as intrusive. The interview could bring forth painful memories, open old wounds or remind the interviewee of dreams never fulfilled. The interviewee can become aware of things they have not reflected upon before the interview and this new knowledge about themselves may affect them. On the other

hand the interviews can also be seen as relieving or healing. How the interview will affect the interviewee cannot be foreseen but it is important to keep this in mind during the interview process⁹⁰. The participants in Paper III-IV received the telephone number of the interviewer in case any matters arose after the interview. A surgeon or a counselor could then be contacted if needed.

Funding of this thesis primarily came from the author's (L.E.) employers and to some extent grants from foundations that did not lay any claims to, or opinions about, the contents of the studies.

MAIN FINDINGS

The papers in this thesis are numbered in the order in which they were carried out. Here they are presented in another, perhaps more logical order beginning with the experiences of living with intermittent claudication followed by the experiences of the spouses. Thereafter, the outcomes of PTA-intervention and finally the health related quality of life after PTA are presented.

EXPERIENCES OF LIVING WITH INTERMITTENT CLAUDICATION

Paper III addressed the experience of living with intermittent claudication. The findings are described in six themes: *Experiencing discomfort in the leg*; *Moving around in a new way*; *Feeling inconvenient when forced to stop*; *Missing previous life*; *Incorporating intermittent claudication in life* and *To lead a strenuous life*. Those themes together founded the main-theme: *Adjusting to a restricted life*.

Living with intermittent claudication means adjusting to a restricted life.

Intermittent claudication greatly influenced daily living. Suffering from intermittent claudication was hovering between wellness and illness. Feeling well when being indoors or sitting still and feeling ill when walking or not being able to do what they wanted. The mere thought of walking could be stressful and made them avoid going out at all. Spontaneous actions were not possible to the same extent anymore and they tried to maintain life through careful planning and constant adjusting.

Changes in the way of moving around were required and alternative transportation always had to be considered. When out walking and pain became overwhelming they had to find a suitable place to stop for a rest. Otherwise they expressed a sense of inconvenience, a feeling of awkwardness or even emotional vulnerability due to the fact that the symptoms were not visible. If no such place was found they could pretend to be waiting for someone, consulting their watch or being interested in something beside the road to justify the place where they stopped.

The illness gave a feeling of being left out of different situations and contexts, being forced to restrictions. The participants expressed that they had to avoid certain activities like travelling with their families or taking part in joint walks and had become dependent on others. Facing the fact that intermittent claudication means a limitation in daily life and learning to live with that was laborious on top of the overall burden of illness. Living with intermittent claudication is living with an invisible illness filled with worries for the future.

SPOUSES' EXPERIENCES OF LIVING TOGETHER WITH A PERSON SUFFERING FROM INTERMITTENT CLAUDICATION

Paper IV addressed the spouses' experiences of living together with someone with intermittent claudication. Four themes were identified: *Frustrating to not meet*

intentions; Undergoing changes in social life; Being a person on the side of things and Intertwining of circumstances. Those themes together founded the overall theme: *Living a demanding life.*

In this study we found that living together with a person suffering from IC was living a demanding life.

It was difficult for the spouses to always be concerned for someone else's wellbeing and not having full freedom. It was also trying to always show consideration and sometimes hard to understand the ill person's situation. The ill person often let their irritation or the bad mood out on the people closest to them, which the spouses saw as unfair. On the whole the spouses had to lower their level of intentions and expectations both at home and in life in general.

The spouses' lives had become restricted, sometimes even confined to the house because of the ill persons' symptoms. It could be trying not being able to make plans and be forced to take each day as it comes, not being able to move about freely and they often felt they had to sacrifice a lot. If they were the kind of couple who used to do everything together there was a big change. The walks they used to take together, this very special way of being together was something they really missed. The spouses who had activities on their own did not notice the change as much. For some spouses the practical sides of daily life at home almost remained the same.

Watching someone close to you suffer from pain, walking disability or isolation could be hard. A feeling of powerlessness was expressed, just being a person standing on the side. It was demanding and mentally straining to both emotionally and physically support someone who used to be the stronger one. The spouses worried about the future and often wondered why the ill person had not sought medical care at an earlier stage.

Apart from the fact that the ill person's symptoms of PAD could take a turn for the worse, there were often other infirmities, different diseases or other aspects related to old age affecting the experience of the situation. The spouses own diseases or infirmities that were concomitants of old age also had to be taken into account. Sometimes the social life was affected more by other disabilities than the impaired circulation.

OUTCOMES AFTER PERCUTANEOUS TRANSLUMINAL ANGIOPLASTY

The characteristics and outcomes of PTA-interventions proximal and distal to the inguinal ligament were described in Paper I. The majority had had symptoms classified as intermittent claudication (N=105) and later amputation was more common in the ischemia group than in the claudication group ($p<0.001$). The patients were younger in the proximal group ($p=0.002$) and more frequently smokers or former smokers ($p<0.001$).

Hematoma/bruise as a complication was more common among non-diabetic patients versus patients diagnosed with diabetes ($p=0.001$). Most of the patients who had

undergone amputation died during the observation period compared to those not requiring amputation ($p<0.001$). Twenty-six PTA-patients (14%) were amputated during the observation period. Eleven out of 38 patients (29%) who had undergone re-operation were amputated compared to 15 of the 150 (10%) not re-operated ($p=0.003$).

Forty percent died during the observation period (follow-up range was 39-95 months). When comparing patients' living situation and mortality, 61% of the deceased patients were living alone, compared to 35% of the survivors, ($p=0.001$). Fifty-four percent of the patients diagnosed with heart disease died during the observation period compared to 32% of the patients without heart disease diagnosis, ($p=0.002$). Twenty-four of the 76 patients who died had previously undergone vascular operations (32%) compared to 13 out of the 112 survivors (12%), ($p=0.001$).

**HEALTH RELATED QUALITY OF LIFE AFTER PERCUTANEOUS
TRANSLUMINAL ANGIOPLASTY**

In Paper II the HRQoL was improved both at the one-month follow-up and the one-year follow-up compared to baseline (see Fig 1 and 2). When comparing SOC and CLAU-S, there was a difference between the groups with low and moderate sense of coherence as well as between the groups with low and high sense of coherence regarding HRQoL (see figure 3).

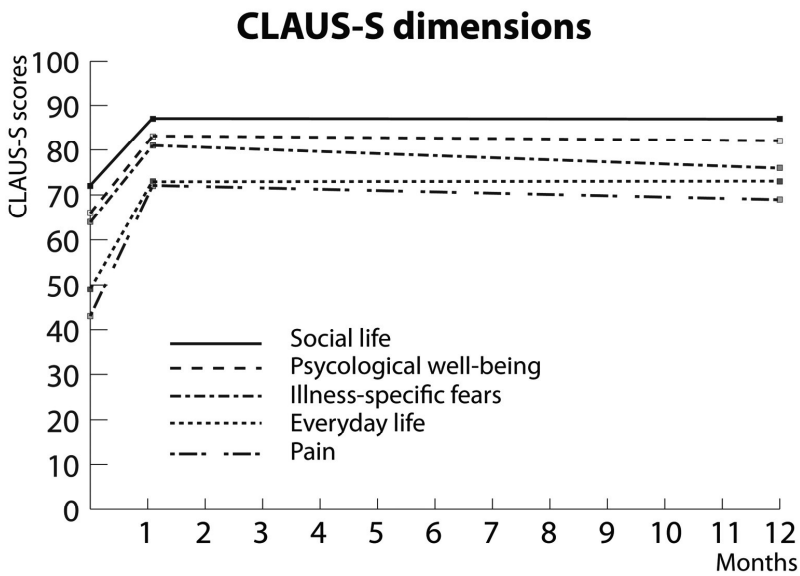


Figure 1. Every aspect of HRQoL described in the CLAU-S questionnaire was affected.

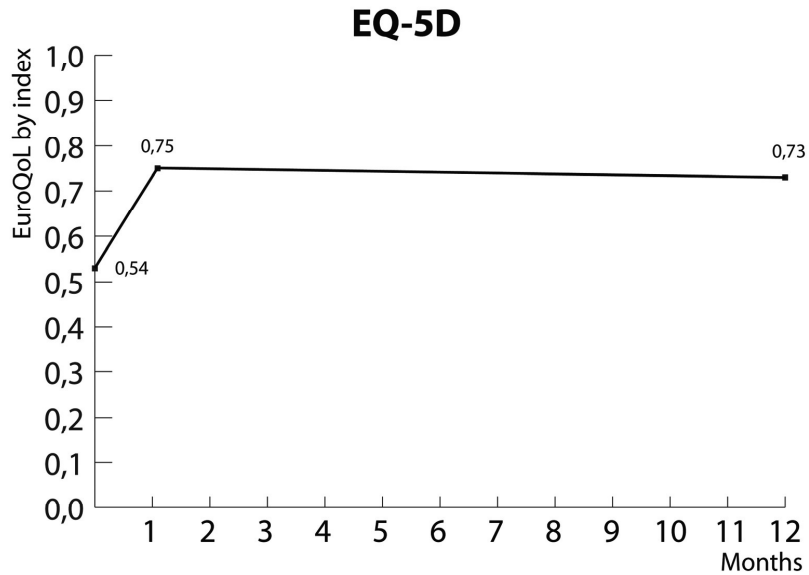


Figure 2. EQ5D computed by index improved significantly both at the one-month follow-up to 0.7504 ($p=0.0006$) and the one-year follow-up to 0.7328 ($p=0.0019$) compared to baseline, 0.5427.

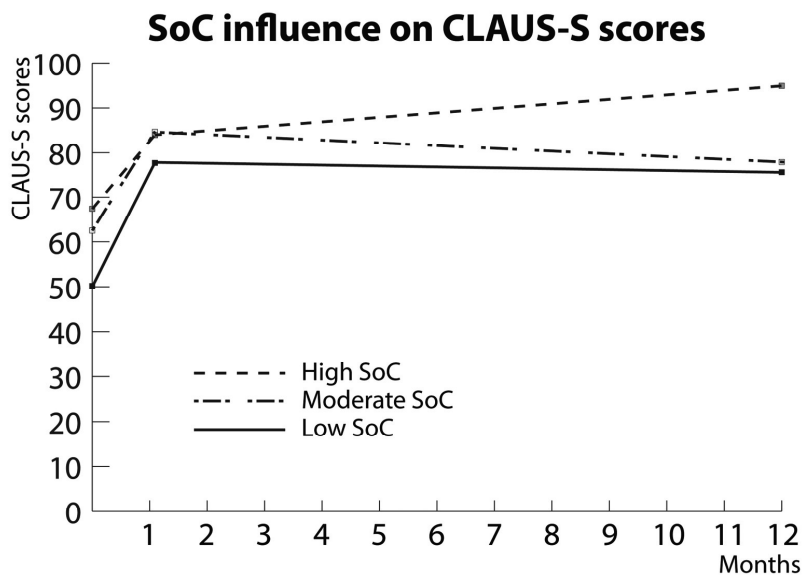


Figure 3. Influence of Sense of Coherence (SoC) score on CLAU-S score.

DISCUSSION

Intermittent claudication as a symptom of PAD has a great influence on daily life. Depending on the severity of the symptoms and their former lifestyle, people suffering from intermittent claudication describe in the interviews how this affected their daily life in different ways. A moderate reduction of the walking ability could be hard to cope with for a formerly very physically active person while it could be quite acceptable for a less active person. With this in mind treatment of people suffering from peripheral arterial disease should focus more on the patient as an individual rather than focusing on the disease and the walking distance. Combining the assessment of functional appraisal e.g. treadmill testing⁵⁹ and the ill person's subjective appraisal of how the symptoms affect that individual is an effective way to find out how the person is really affected by the symptoms. Measuring only objective function will not give the proper picture of living with PAD because as stated by Breek¹¹², "Objective functioning and subjective appraisal are complementary and not identical". To deepen knowledge and understanding of the experiences of people living with PAD and their family members it is important to listen to their stories.

Impaired walking ability

The symptom intermittent claudication, is cramping or aching in the leg while walking which is relieved by a rest¹. This means that people suffering from intermittent claudication are forced to stop and not always in a suitable place. The participants suffering from intermittent claudication described the importance of finding the right place to stop for a rest. They wanted the appearance of an apparent reason; otherwise they expressed a sense of inconvenience, partly because they felt observed. The participants could not really explain why they felt and behaved like this but one reason could be to avoid being seen as disabled. Treat-Jacobsson et al¹² and Crosby et al⁵⁴ had similar findings, where the reduction of the walking ability lead to feeling abnormal, conspicuous and different when being forced to stop repeated times when out walking. Among the participants the uncomfortable feeling when stopping could also depend on the fact that the symptoms were not visible. Having a good reason to stop when walking alone could feel better or walking in the company of someone because they then could find a reason to stop while pointing at something they pretended to be interested in. Some did not have a partner or friend to walk with and others felt they did not want to be a bother to anyone else and for that reason refrained from walking. To avoid being out walking with all that this implies as a means of exercise may also have negative effect on their health situation since exercise therapy improves the walking ability and works as a sustainable choice of treatment in peripheral arterial disease¹¹³. The participants described the value of walking together with others since it becomes more natural to walk at a slower pace and to stop somewhere for a rest. Some of the participants even expressed that they would have preferred organized exercise. Supervised exercise has been shown to increase walking ability which was associated with improvements of quality of life in all but one study in a review¹¹⁴ of all exercise-based interventions between 1989-2008 assessing quality of life in people with intermittent claudication.

Health related quality of life and outcomes after percutaneous transluminal angioplasty

The HRQoL was improved both at the one-month follow-up and at the one-year follow-up after PTA-intervention compared to baseline. Improved HRQoL after PTA has also been presented in other studies^{4-9, 115}. Measuring the patient's perspective of medical outcomes should play a role, just as important, as established measures like treadmill walking distance or patency rates, to determine who should receive PTA treatment¹⁰ as well as to evaluate the outcome of PTA. Patient reported outcomes are important to capture the full picture of the effects not only of the disease, but also of the treatment because clinicians tend to underestimate or overestimate HRQoL in patients and rely too much on the severity of the disease¹¹⁶. Aquarius et al¹¹⁷ studied if the subjective reports of impaired health status and QoL of people with intermittent claudication were significant determinants in physicians' clinical decisions of invasive interventions. They found that poor physical functioning both reported by the patient and measured by treadmill walking were predictors of invasive treatment, while perceived experiences of poor physical functioning were not.

When comparing sense of coherence with the SOC and health related quality of life with CLAU-S in patients with PAD undergoing PTA, there was a difference between the groups with low and moderate SOC, as well as between the groups with low and high SOC regarding HRQoL. The group with low SOC scored worse in HRQoL in relation to those with moderate and high SOC. Patients with high SOC scores estimated their quality of life higher than patients with low SOC scores had done in other studies^{7, 80-81}. Together with ankle brachial index a high sense of coherence score was the only independent predictor for high scores in QoL in a previous Swedish study regarding surgical revascularization of PAD⁷.

Regarding outcomes of PTA we found that a higher percentage of the patients in the proximal group were younger and were also smokers or former smokers. As Willingendael³⁶ recommends, we chose to put smokers and former smokers in the same group because the prevalence of PAD among former smokers is closer to that of current smokers than the prevalence of PAD among never-smokers. Smokers or former smokers have more proximal problems¹¹⁸ and it is well known that smokers are diagnosed with PAD approximately ten years earlier than non-smokers³². Amputation was a strong predictor of death during follow-up since most of the patients who had undergone amputation died during the observation period compared to those not requiring amputation. A possible explanation for this could be that people requiring amputation had more severe underlying arteriosclerosis, which is a strong predictor of death³², whereas amputation as an intervention is not. Concerning complications after PTA we found 52 patients (28%) with hematoma/bruise recorded as a complication. This is a high rate compared to previous studies^{86-87, 119} and this discrepancy may be the result of the fact that all hematomas/bruises documented in the patient records were included in this study, no matter their size. In earlier studies the criteria for defining a hematoma were not provided, which might mean that smaller bruises were excluded. Another finding regarding complications after PTA was that hematoma/bruise as an access site complication was three times more common among non-diabetic patients than those with diabetes. A possible explanation for this could be that people diagnosed

with diabetes have less severe proximal arteriosclerosis of the lower limb compared to people with PAD not diagnosed with diabetes^{118, 120}.

Missing previous life

People living with PAD describe how the disease changes and effects the body and its' functions, i.e. the walking ability, and how they are not able to control these changes. When pain became overwhelming it was not possible to continue and they expressed how they just had to stop for a rest. Even if it is never possible to totally control even a healthy body, there is a significant change when a person is stricken by illness²⁶. Those suffering from PAD also describe how the pain affects them differently, different days. Furthermore they missed their previous life when they were healthy and not as restricted as is also described in previous studies^{13, 52-54}. To perform certain activities and belonging to certain social networks is a part of the self-image. A feeling of no longer belonging or contributing challenges peoples' self-image and personal identity¹²¹.

The participants with intermittent claudication expressed that the situation was hard to accept because at rest they felt much healthier than they actually were and they did not want to be seen as invalids. At the same time they expressed that they felt worse than what was visible from the outside. They stated that people around them could think of them as more unwell than they felt or vice versa and the fact that they did not have the same idea about their illness as those around them and the fact that those around them did not understand what it was like having these symptoms was seen as a problem. They wanted to take care of themselves and not be pointed out as someone miserable or someone to feel sorry for. This could mean refraining from doing things they wanted to do rather than accepting help from others and being a burden to others. The feeling of being a burden to others has been seen in previous studies of living with PAD¹²⁻¹³ but also in other studies concerning chronic illnesses such as chronic heart failure as presented in a review by Jeon et al¹²². To be clear with how you want to be treated can be very important for the person living with illness since people around have a tendency to not ask or simply take for granted that the ill person always needs help with everything which is something that can lead to both conflict and grief²². Being restrained from handling everyday tasks or walking certain distances could be exasperating for the ill person and the whole situation could make them furious. All this affected their mood negatively and in the end affected the people around them leading to quarrels between spouses, for example. This issue was also brought up in the interviews with the spouses. The ill person often took their frustration out on the people closest to them. This was something the spouses saw as unfair but had to cope with. Some of the spouses thought that they ought to be more understanding than they actually were but it was hard to understand the pain or the reduced walking ability when they did not feel it themselves.

The participants living together with someone suffering from intermittent claudication missed their earlier life together and the relationship could be negatively affected, at least temporarily. Out of consideration for the ill person they did not do any of their former activities. They could end up sitting together on the sofa at home without anything to do which could be very frustrating. The personal relationship could be

affected by the bad moods or irritation for both spouses just as Brubaker¹²³ has reported for other couples with diminishing health. The spouses of people with chronic illness could develop a feeling of being trapped and often have to make difficult choices between themselves and the ill person^{31,77}. Engström et al³⁰ describe that for spouses it could mean putting themselves in second place to be able to support the ill person. Previous studies have found that when spouses prioritize themselves they can develop feelings of guilt^{31,77} and when they prioritize their ill partner they develop feelings of isolation and reduction of freedom⁵⁵. The spouses in our study found it hard to give up their common life and missed the togetherness during joint walks and their ill partner's walking impairment also resulted in less social activities as also seen in previous studies^{55,77,124}. The participants living with someone suffering from intermittent claudication worried about the future and expressed that it was mentally straining to both emotionally and physically have to support someone who used to be the stronger one. This has been seen in earlier studies^{31,77} where spouses of people living with illness do not only worry about their partners but also about the consequences of the illness for their own situation.

Incorporating intermittent claudication in daily life

The interviews with people suffering from intermittent claudication reveal that the participants to some extent have learned how to manage every day life with the symptoms. A woman expressed that she now knows that there are certain things she can do and other things she cannot do and that is just the way things are. One has to concentrate on the important things in life instead. Wann-Hansson et al¹²⁵ interviewed people with peripheral arterial disease about their long-term experiences and the recovery following revascularizations. They found that when people learned how to handle restrictions in life they were able to move forward and to handle their life situation in a better way. This can be related to the women with multiple sclerosis in the study of Olsson et al¹²⁶ who did not take things in life for granted and with a different perspective on life, could focus on the important things in life.

To maintain every day life as normal as possible is important to handle life with illness²⁴. To struggle for normality is linked to understanding why one has become ill and also understanding the changes in one's life situation and finding new ways to integrate these changes in life¹⁵. Things taken for granted earlier in life are not working anymore¹⁹ but it is possible to adapt to the new life situation that includes the illness by finding strength in the will to feel better and to regain control of daily life²⁷ or by becoming aware of the things that are good and healthful in life. Some of the participants suffering from intermittent claudication stated that nothing they wanted to do was unsolvable. They just had to do it in another way, like taking the car or asking people to visit them instead of the opposite. What living a normal life means has to be considered from their own perspective, a perspective that now includes the illness and its' symptoms as well as how these symptoms are handled. To find balance in life the ill persons can develop different strategies where they try to keep their positive attitude and to accept the situation (living with chronic illness)²⁴. The participants stated that feeling bitter or complaining about the situation would do no good and was definitely not the solution. One way to handle such feelings was to imagine things could always be worse. By making changes in life style and by accepting certain limitations in life

they can continue to lead a normal life²⁴. Incorporating intermittent claudication in life could be facing the fact that the symptoms mean a limitation in daily life. The participants now had to conform their daily life into a life with a walking disability. Living with chronic illness radically changes life. Seeking normality is a part of living with the illness and the ill persons themselves become experts on how to live with the illness, sometimes with the illness only in the background and sometimes it dominates life²⁹. This corresponds to what Öhman et al¹⁵ showed, those living with chronic illness fought to live their life as normal as possible and learned to live with their illness by for instance avoiding certain situations that could make the illness worse.

Peripheral arterial disease and other infirmities

In the interviews with the spouses we found that apart from the fact that the ill person's symptoms of PAD could take a turn for the worse, there were often other infirmities, different diseases or other aspects related to old age affecting the experience of the situation. Sometimes the social life was affected more by other disabilities than the impaired circulation. This could be related to that symptoms of intermittent claudication often come gradually and could be mistaken as being a consequence of the ageing process⁵⁴. The coexistence of natural ageing and illness makes it hard to distinguish the effects of one specific diagnosis and the symptoms thereof on daily life, since reduced mobility according to Person et al¹²⁷, is also a part of natural ageing. Sometimes other infirmities can be hidden behind the symptoms of PAD. Wann-Hansson et al.¹²⁵ found that the revascularization also revealed other ailments when people suffering from PAD were relieved of the PAD symptoms. These "new" symptoms could derive from other diseases or from the underlying arterial disease, for example cardiac symptoms¹²⁵. The spouses of people suffering from intermittent claudication expressed that they also had infirmities of their own and this could be straining for both themselves and the ill person. In the interviews with people suffering from intermittent claudication, the other infirmities, diseases or other aspects related to old age did not surface as clearly. A possible explanation for this is that it is easier for them to define and separate one infirmity/symptom from another while the spouses, who see the ill person and his/her situation as a whole, might have difficulties to tell the different infirmities or symptoms apart. It is important to be able to see the whole picture of the ill person and the ill person's life and for this reason it is essential to gain knowledge from the spouse's perspective. Jeon²⁴ describes how medical expertise, often focusing on their own field, rarely is able to see the whole picture. The spouses own diseases or infirmities that are concomitants of old age also have to be taken into account since today they are important as informal caregivers. Apart from the importance of having the spouse's perspective to deepen the understanding of the ill person's experiences and daily life, it is also important to have the spouse's perspective for their own sake, to be able to treat and support them.

CONCLUSIONS AND CLINICAL IMPLICATIONS

- Living with intermittent claudication has a major impact on daily life and demands adjustment to a restricted life. Apart from the severity of symptoms, experiences of living with the illness are different depending on how active the ill person is or wants to be.
- Ageing and living together with someone suffering from intermittent claudication, a symptom that has great impact on both the spouse's and the ill person's life, is demanding and complex.
- Percutaneous transluminal angioplasty improves health related quality of life among individuals suffering from peripheral arterial disease and the effect is also sustainable over time up to one year after the intervention.
- No differences in outcome were found between patients who had undergone percutaneous transluminal angioplasty whether proximal or distal to the inguinal ligament; however the patients were younger in the proximal group. Hematomas/bruises as a complication after percutaneous transluminal angioplasty were more common among non-diabetic patients.

This thesis contributes to the knowledge and understanding of the life situation of people living with peripheral arterial disease and their family members and emphasize the importance of having both the ill person's and their family members' experiences of the situation when supporting them or making decisions regarding treatment. It seems to be important to ask family members about their health status and life situation in order to properly support them. With the shorter hospital stays of today, people with illness are discharged from the hospitals with extensive needs of help and care. It is often taken for granted that spouses or other family members can give this help and support. The symptoms of peripheral arterial disease have a great influence on daily life but affect daily living in different ways depending on the severity of the symptoms and the ill person's former lifestyle.

FUTURE RESEARCH

As shown in this thesis peripheral arterial disease has great impact on the daily life for both individuals suffering from intermittent claudication and their spouses and that health related quality of life increased for those undergoing percutaneous transluminal angioplasty. Regarding experiences, two sides of the same coin, emerge in the interviews with individuals suffering from intermittent claudication and their spouses respectively. Future studies could deepen the understanding of the ill person's and the family member's different perspectives and could be the foundation for better treatment and support for both. In future studies it would be of interest to find out:

- the strategies people living with peripheral arterial disease and their family members have for handling daily life.
- the different experience from the perspective of the men and women who live together with someone suffering from peripheral arterial disease.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Livssituationen hos personer med benartärsjukdom och deras närstående

Att leva med långvarig sjukdom kan ofta leda till att livet blir inskränkt, att man tappar kontrollen över livet och social isolering. Både fysiska och sociala funktioner påverkas ofta negativt och att leva med sjukdom kan också ge en känsla av att bli en börda för andra.

Livssituationen hos dem som drabbas av benartärsjukdom och den nedsättning av gångförmågan som det innebär leder till stora inskränkningar i det dagliga livet och bidrar till en försämrad livskvalitet. Den vanligaste orsaken till benartärsjukdom är arterioskleros som leder till förträngningar i blodkärlen som i sin tur leder till ischemi (syrebrist) i benmuskulerna. Detta kan visa sig på olika sätt. Mindre grav ischemi kanske inte märks alls eller visar sig som claudicatio intermittens (fönstertittarsjuka). Den drabbade får då ont i benen efter att ha gått en viss sträcka och måste sedan vila, för att bli av med smärtan. Värre symtom som vilosmärter eller sår och gangrän benämns som kritisk ischemi. Riskfaktorer bakom arterioskleros är rökning, högt blodtryck, diabetes och höga halter av blodfetter. Risken att drabbas ökar också med åldern.

Det övergripande syftet med avhandlingen var att öka förståelsen för livssituationen hos personer som lider av benartärsjukdom och deras närstående.

De personer som ingår i två av de fyra delstudierna har genomgått perkutan transluminal angioplastik (PTA), d.v.s. ballongvidgning av förträngningar i kärlen som är en behandlingsmetod vid benartärsjukdom. Ingreppet innebär att med hjälp av en tunn kanyl föra in en specialkonstruerad kateter i kärl med stenoser eller ockklusioner. Katetern är utrustad med en ballong i ena änden och denna ballong placeras i höjd med förträngningen och blåses upp varpå kärlumen dilateras och blodgenomflödet förbättras.

Syftet med **Delarbete I** var att beskriva medicinska effekter och påverkan på det dagliga livet hos personer som genomgått PTA över och under lumskligamentet mellan åren 1998 och 2002 på ett sjukhus. Det var en journalgranskningsstudie där ett undersökningsprotokoll utarbetades och användes vid insamling av samtliga data. Resultaten visade att det fanns ett samband mellan ingrepp ovanför lumsken och ålder liksom mellan ingrepp ovanför lumsken och rökning. De som genomgått ballongvidgning över lumsken var yngre och oftare rökare än de som genomgick ballongvidgning under lumsken. Blödning eller blåmärke som komplikation efter ingreppet var vanligare hos de som inte hade diabetes.

Syftet med **Delarbete II** var att undersöka hälsorelaterad livskvalitet hos personer med benartärsjukdom som genomgått PTA upp till ett år efter ingreppet. Data samlades in med hjälp av två olika hälsorelaterade livskvalitetsformulär, ett generellt (EQ5D) och ett sjukdomsspecifikt (CLAUS), som inför den här studien översattes till svenska. Resultatet visade att ingreppet förbättrade den hälsorelaterade livskvaliteten hos

personer med benartärsjukdom i jämförelse med hur livskvaliteten skattades före ingreppet och höll sig stabil fortfarande ett år efter ingreppet.

Syftet med **Delarbete III** var att beskriva upplevelsen av att leva med claudicatio ur ett inifrånperspektiv. Kvalitativa intervjuer genomfördes med 15 personer som har benartärsjukdom med claudicatio som symtom. Intervjuerna analyserades med kvalitativ innehållsanalys och sex teman bildade tillsammans huvudtemat som handlade om att anpassa sig till ett begränsat liv. Upplevelsen att leva med claudicatio beskrevs som besvärlig eftersom de drabbade fick anpassa sig till ett begränsat liv, där noggrann planering krävdes och spontana handlingar nästan var omöjliga. Att behöva stanna på "onaturliga" ställen när smärtan blev för svår kunde upplevas som besvärande och pinsamt.

Syftet med **Delarbete IV** var att beskriva upplevelsen av att leva tillsammans med någon som lider av claudicatio. Tio makar och sammanboende till de som lever med benartärsjukdom och har claudicatio som symtom intervjuades. Intervjuerna analyserades med kvalitativ innehållsanalys och det övergripande temat handlade om att leva ett påfrestande liv. De närstående oroade sig för den drabbade och det var svårt att se någon som inte längre kunde gå på samma sätt och kanske därigenom också isolerade sig. Förutom att de saknade sitt tidigare gemensamma liv, så kunde de själva inte längre göra saker som de tidigare gjort och det sociala livet förändrades. Resultaten av den här studien visar också på komplexiteten och svårigheterna av att åldras och leva tillsammans med någon som lider av claudicatio, då både de egna och den sjukes andra krämpor, sjukdomssymtom och åldrandet i sig påverkar livssituationen.

För att förstå hur det är att leva med en långvarig sjukdom som till exempel perifer benartärsjukdom är det av stor vikt att få den drabbades perspektiv på att leva med sjukdom i det dagliga livet. Genom att lyssna på berättelser av personer med olika sjukdomar, så kallade sjukdomsberättelser, kan vi lära oss mer om hur det är att leva med olika sjukdomar.

Denna avhandling ger fördjupad kunskap om och förståelse för livssituation hos dem som lever med benartärsjukdom och understryker vikten av att få med både patientens och den närståendes upplevelser av situationen vid möten med patienter i vården och vid beslut om vård och behandling. När det gäller vad benartärsjukdom ger för effekt mäts ofta maximal gångsträcka, vilket inte talar om hur personen upplever sin situation. Det är därför viktigt att ta reda på vad den gångsträckan betyder för den drabbade och dennes livssituation. För de som är mycket fysiskt aktiva kan också en liten inskränkning av gångförmågan vara mycket handikappande medan den för kanske mer stillasittande personer kan vara helt acceptabel.

En djupare förståelse av hur det är att leva med långvarig sjukdom och hur både de drabbade och deras närstående påverkas av långvarig sjukdom behövs för att kunna utveckla vården och för att kunna bemöta de som lever med långvarig sjukdom på ett bättre sätt, där människors berättelser om hur det är att leva med sjukdom uppmärksammas.

Framtida studier som ger ytterligare kunskap om både den sjukes och de närståendes perspektiv bidrar till en rikare beskrivning av den sjukes situation. Dessa båda perspektiv bidrar till att se helheten av livssituationen för den sjuke och kan därmed ligga till grund för ett bättre bemötande och omhändertagande av dem båda.

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